

# Patient information from BMJ

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## Fetal alcohol spectrum disorders: what is it?

Children whose mothers drink alcohol heavily while pregnant can have serious physical and mental health problems, including birth defects, brain damage, and learning difficulties.

If you think that your child might be affected in this way, there are treatments that can help. You can use our information to talk with your doctor about what might help your child the most.

### What are fetal alcohol spectrum disorders?

Fetal alcohol spectrum disorders (FASD) is a term that covers the various problems that can affect children whose mothers drank heavily or had problems with alcohol while pregnant.

You might hear doctors use different terms to describe these problems. For example, they might talk about:

- fetal alcohol syndrome
- alcohol-related neurodevelopmental disorder, and
- alcohol-related birth defects.

These terms all mean something slightly different, but they all deal with the damage caused by alcohol. And the treatment for each one focuses on what is best for each individual child.

### How much alcohol is too much?

The simple answer is that we don't know. Everyone is different. Not every child whose mother drinks alcohol while pregnant will have problems. And we don't know whether there is a "safe" level of drinking during pregnancy.

To be on the safe side, pregnant women are usually advised to drink very little alcohol while pregnant - no more than one or two small drinks per week - or, better still, not to drink at all.

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## How does alcohol harm babies?

Alcohol causes harm because it “crosses the placenta”. That means that it spreads from the mother’s bloodstream into the part of the womb that nourishes the baby as it grows. So the alcohol that the mother drinks also affects the baby.

This can cause damage to the baby’s brain and nervous system, which can cause problems including:

- low birth weight
- birth defects
- unusual facial features
- slow growth delays in reaching development milestones, such as walking, talking, and holding objects
- learning difficulties
- behavior problems, and
- problems interacting with other people.

The baby can be affected in other ways, too. For example, a pregnant woman who drinks heavily might be struggling with mental-health problems, and struggling to take care of herself and to eat properly.

This might mean that the baby doesn’t get the nutrition it needs to grow in a healthy way.

## Problems in older children and adults

As children affected by FASD become teenagers and then adults, they can have a number of problems. For example, young people and adults with FASD are more likely to struggle with mental-health problems, such as:

- depression
- anxiety
- psychosis (seeing and hearing things that aren’t there)
- learning difficulties, and
- personality disorders.

Social problems are also common in people with FASD. For example, if FASD affects you, you are less likely to stay in education, find and keep a job, and live independently and take care of yourself.

And you are more likely to have contact with the police, and to abuse drugs and alcohol.

Some people with FASD also have difficulties with social behavior, friendships, and relationships. In particular some people struggle with what is and is not appropriate sexual behavior.

### What are the symptoms?

The symptoms listed here cover all ages from babies through to adults. And they won't all affect everyone with FASD. But if your child is affected by FASD, you will probably recognize several of them. Symptoms of FASD include:

- low birth weight - your baby might also have been born preterm (early), which means before 37 weeks into pregnancy
- poor feeding as a baby
- being irritable and short tempered as a baby and child
- being shorter than average at birth and probably throughout life
- a head that is smaller than average
- unusual facial features, such as small eyes, a thin upper lip, and a smooth philtrum (the philtrum is the space between the nose and upper lip). But these features can often become less noticeable as children grow
- fingernails that are small and poorly developed
- bent or mis-shapen fingers
- being cross-eyed (doctors call this "strabismus"), and
- hearing and vision problems.

Some children don't have any physical symptoms of FASD. But they might be diagnosed when they see a doctor because of other problems, such as difficulties with learning or behavior.

During a discussion about the child's development, it might become clear that the mother had issues with alcohol during pregnancy. This helps the doctor to understand the child's issues and, hopefully, to recommend treatment.

### How is FASD diagnosed?

If you are the mother of a baby or child with suspected FASD, your doctor is going to ask you some difficult questions about your drinking during pregnancy.

These questions can be hard to face. But it's important to answer them honestly.

Your doctor is not judging or blaming you. He or she just needs to know as much as possible about you and your child, so that your child can get the best treatment and have the best future possible.

Before diagnosing a child with FASD, doctors will look at four specific questions:

- Did the child's mother drink alcohol heavily while pregnant?
- Does the child have some of the facial features common in children with FASD?
- Does the child show signs of slow or reduced growth?

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- Does the child show signs of problems with the nervous system: for example, did the child have a small head when born, or does he or she have problems with reflexes and lack of coordination?

Your doctor is not judging or blaming you. He or she just needs to know as much as possible about you and your child, so that your child can get the best treatment and have the best future possible.

X-rays and other imaging tests can also check for problems with the bones and muscles that are common in people with FASD. Your doctor might also want to do some tests to check if your child has a genetic condition that might be causing his or her symptoms.

Doctors often want to keep an eye on babies born to mothers who had problems with alcohol during pregnancy, even if the baby has no symptoms. This is because symptoms often aren't noticeable until school age.

### Moving forward after diagnosis

You might find it upsetting if your child is diagnosed with FASD. And you might have feelings of guilt or failure.

But the diagnosis can be a positive step. Parents and carers often struggle to understand a child's issues for years before a diagnosis makes things clear. A correct diagnosis can bring relief, and gives parents and carers the chance to:

- identify a child's strengths and weaknesses
- praise and promote the child's strengths while helping with areas where they are less strong
- understand what a child is going through, and
- adjust their expectations.

### What will happen?

A big part of helping a child with FASD is simply learning about the condition. So your doctor should give you useful information about how your child is affected, and about what you can do to understand and to help.

This should include information about:

- community services
- government and educational support, and
- local parent-help groups that provide information and support for children and their families.

Unfortunately there is no cure for FASD, and children don't grow out of it or get better. The outlook for an individual depends on many things, including:

- getting an accurate diagnosis as young as possible

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- how severely he or she affected to begin with
- whether treatment is helpful, and
- having a home life that is as stable, nurturing, and understanding as possible.

Children and young people with FASD should have a review with their doctor at least once a year, to check their progress and assess whether they need extra help. Your doctor will check up on progress and any problems with things like:

- movement, speech, and language
- education
- social skills
- behavior and mental health
- drug and alcohol issues
- complications of any birth defects.

Many children with FASD do well with the right support and treatment, and there are success stories. But, for many, life is tough.

Without the right help, most children with FASD struggle to stay in education and employment. Only about 14 in 100 young adults with FASD live independently. Most live in institutions or assisted-living settings.

Many young people with FASD find themselves in trouble with the law, and many have problems with mental health and with alcohol addiction.

There are many organizations and charities that help children with FASD and their families and carers. Your doctor might be able to help you find a support group in your area, or you could search online.

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